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Communication

The Durban World Congress Ethics Round Table IV: Health care professional end-of-life decision making

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ABSTRACT

Introduction: When terminal illness exists, it is common clinical practice worldwide to withhold (WH) or withdraw (WD) life-sustaining treatments. Systematic documentation of professional opinion and perceived practice similarities and differences may allow recommendations to be developed.
Materials and methods: Speakers from invited faculty of the World Federation of Societies of Intensive and Critical Care Medicine Congress that took place in Durban (2013), with an interest in ethics, were approached to participate in an ethics round table. Key domains of health care professional end-of-life decision making were defined, explored by discussion, and then questions related to current practice and opinion developed and subsequently answered by round-table participants to establish the presence or absence of agreement.
Results: Agreement was established for the desirability for early goal-of-care discussions and discussions between health care professionals to establish health care provider consensus and confirmation of the grounds for WH/WD, before holding formal WH/WD discussions with patients/surrogates. Nurse and other health care professional involvement were common in most but not all countries/regions. Principles and practical triggers for initiating discussions on WH/WD, such as multiorgan failure, predicted short-term survival, and predicted poor neurologic outcome, were identified.
Conclusions: There was majority agreement for many but not all statements describing health care professional end-of-life decision making.

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1. Introduction

Approximately 10% to 30% of all emergency admissions to intensive care units (ICUs) will die in the ICU; [1-3] and, therefore, management of the dying process is a necessary skill for all ICU health care professionals. Life-support technology has advanced, so that it is now possible to maintain vital organ function, despite the realization that a return of the patient to reasonable health and an acceptable quality of life are no longer possible. When a return to reasonable health is no longer possible, it has become common clinical practice worldwide for ICU staff to limit life-sustaining treatments (LSTs) by withholding (WH) or withdrawing (WD) LSTs [4-12]. There are, however large differences in the practice of WH/WD in different parts of the world as evidenced by responses to several surveys that have explored physicians' practice and ethical views on the subject [13-20]. This self-reported variation in the pattern of practice of health care practitioners has been confirmed by observational studies that also demonstrate regional variations in practice [4-12]. Although guidelines for some jurisdictions do exist, [21-25] and are often useful, they sometimes lack sufficient detail to guide daily practice and seldom consider the variability inevitably introduced by cultural and regional differences. Although cultural and social differences are slow to evolve, people in the modern world migrate in large numbers, with ease and over great distances. It is thus important that ICU health care professionals are aware of similarities and differences in international end-of-life practice and expectations [26-28].

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The decision to initiate the process of WH/WD for a particular patient is a complex one and one that involves several stakeholders. To begin with, it requires recognition that WH/WD is potentially justified, followed by a process to confirm the appropriateness of WH/WD. Lastly, it must be demonstrated that the decision to proceed is in the best interests of the patient himself/herself. This article will focus specifically on the initial part of the end-of-life process, that is, making the decision to proceed to WH/WD discussions with the family. With information drawn from the results of an international meeting of experienced clinicians with an interest on end-of-life care, we have documented similarities and differences in the way the above process is managed around the world, and where sufficient similarities were shown to exist, have developed statements of general agreement.

2. Methods

Speakers from the invited faculty list of the World Federation of Societies of Intensive and Critical Care Medicine Congress, held in Durban September 2013, were approached by the conference scientific convener to participate in the ethics round table. All round table participants had a known interest in ethics. Round table participants were asked to identify what in their opinion constituted the 3 most pressing specific worldwide ethical issues that the group should address. Most responded that end-of-life issues, including WH and WD LSTs constituted the most important issue. Seventy questions related to end-of-life care in ICU were sent to participants.

Before the round table discussion held in Durban, participants were asked questions by e-mail circulation to determine local practice in their hospitals and countries, in relation to the clinical practice of end of life. There were 20 responses with similarities and variations from different countries that seemed the most interesting (decision by author CS). The summary of these responses was sent to all participants by e-mail before the face-to-face meeting. Respondents were asked to identify the most important and relevant topics from this list and to then prepare for face-to-face discussion at the Congress. The 5 topics with the greatest clinical importance and differences between centers and countries were chosen by agreement at the face-to-face round table discussion. They included questions related to WH and WD LSTs at the end of life for age, health care professional end-of-life decision making, patient/family end-of-life decision making, how to withdraw mechanical ventilation, and differences between WH and WD LSTs. The focus of this article is to describe the process of health care professional end-of-life decision making. To further define key issues in this process, discussion in Durban identified the following key questions related to the focus of this manuscript:

(1) Is there a need for consensus by any, some, or all stakeholders when making decisions to proceed to WH/WD?
(2) If consensus is required, is there or should there be a specific sequence by which ultimate consensus is achieved among all stakeholders?
(3) Should goal-of-care discussions routinely take place, and when should they be initiated?
(4) Which parties are or should be responsible for the initiation, discussion, and decision-making processes?
(5) What “general principles” justify the decision to consider WH/WD life support?
(6) What “specific clinical factors” trigger decisions to proceed to discussions and decisions on WH/WD?

After the meeting, questions were developed to provide an overview of current practice and opinion related to the questions. Questions were tested for validity by giving all participants an opportunity to comment on, add, or change questions (using e-mail). This resulted in a final set of questions that were answered by round table participants. A total of 76 questions were finalized, using a Likert scale format (strongly agree, agree, neutral, disagree, and strongly disagree), with a free-text options for comment. The answers that specifically relate to the stated questions that are the focus of this report are section II, health care professional end-of-life decision making. Questions from this section have been renumbered from 1 to 30 for clarity (Appendix 1).

3. Results

A list of round table participants can be found at the end of the manuscript. The final set of questions that was developed and then answered by e-mail circulation can be found in Appendix 1, and results are presented in the order of the goals set out in the methods. The responses to the final questions developed by the round table group are shown in Tables 1 to 3. To simplify the presentation of results, the Likert scale format (strongly agree, agree, neutral, disagree, and strongly disagree) was simplified by grouping strongly agree and agree and strongly disagree and disagree. Results to questions are presented in order, corresponding to the key questions stated in the methods.

(1) At the original round table discussion, it was evident that there were differences in practice relating to the need for consensus among professional health care providers before engaging the family in discussions. Therefore, to characterize the process before a formal family/surrogate discussion, the following considerations were explored: question 1 explored the possibility of discussing patient preferences regarding WH/WD in general (statement A) or general values, goals, and preferences without specific mention of WH/WD (statement B). Table 1 documents participant responses on these key issues to be addressed before holding a WH/WD discussion with the family and favored the need to explore patient preferences and values before WH/WD discussions.
(2) Question 1 (statements C-F) explored the requirement, if any, for reaching a medical consensus before having a WH/WD discussion with the family. Participant responses are documented in Table 1 and generally favored the need to achieve medical consensus before family discussion.

Table 1
Participant views on key issues to be addressed before holding a WH/WD discussion with the family, including early goal-of-care discussions

		Agree	Neutral	Disagree	All
1	Before WH/WD discussions with the family				
1A	Initial discussion—explore patient WH/WD preferences	17	1	3	21
1B	Initial discussion—explore patient values, goals on WH/WD	18	2	2	22
1C	Hold discussions with the primary care physician	19	3	0	22
1D	Discussions with other intensivists	20	1	1	22
1E	Discussions with nursing staff	19	2	1	22
1F	Discussions with both physicians and nurses in ICU	19	2	1	22
2	Goal-of-care discussion				
2A	Early goal-of-care discussion—general medical issues	17	3	2	22
2B	Early goal-of-care discussion—info on WH/WD issues	8	8	6	22
	WH/WD discussions should occur in response to:				
3	Patient/family requests (including advance directives)	19	0	3	22
4	Physician requests	20	1	1	22
5	Nurse requests	16	3	3	22
		Agree	Neutral	Disagree	All
8	Reported participation ICU nurses in ICU rounds	18	2	2	22
9	Routine formal discussions on WH/WD with nurses	16	0	6	22

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